ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

DECEMBER 1988

UFMCC BENEVOLENCE FUND

(By Rev. Ron Russell-Coons)

Every week I can count on receiving a phone call from the business office of the University of Washington Hospitals. Each week it's the same plea; "pay your bill immediately so that we won't have to turn you over to a collection agency." I've tried to avoid letting the calls stress me out, but that's not easy. My bills only amount to about $3500.00. I wonder how patients who owe three or four times that amount must feel.

Reality: more and more of our clergy and their spouses will face insurmountable medical expenses. Whether due to accidents or illnesses, the last thing that people need is to have bill collectors hounding them. Because of the need to assist our clergy in such situations, the General Council of UFMCC established a Benevolence Fund in October of 1987.

Many of our churches responded to this Fund and a number of individuals have been helped. I am one! I gratefully received a check in the amount of $500 last January which helped tremendously with hospital and doctor bills. For a while, at least, the collectors were content.

The Benevolence Fund is on-going. Perhaps this holiday season you would like to make a donation to the Fund in memory of someone..or perhaps to honor someone. Though you may never hear a direct testimony from the recipient, you can know that your gift was deeply appreciated.

Send donations..in any amount to the UFMCC Benevolence Fund, c/o Elders, 5300 Santa Monica Blvd., #304, Los Angeles, CA 90029.

LIVING WITH AIDS: REACHING OUT

(Author: Tom O'Connor)
(Book Review by: Rev. Ron Russell-Coons)

Tom O'Connor presented me with a copy of Living With Aids while we were "doing lunch in the Castro." I heartily recommend Living With Aids because it is a helpful resource, but also because I have grown to appreciate the author as a sensitive, caring friend. Tom does not write about Aids as an outsider. Instead, Living With Aids is for those who are HIV+ by someone who is HIV+.

Though some prefer to passively relinquish the power to make healthcare decisions, others, like Tom and myself, believe that we are in control. By becoming educated about HIV, related infections, and our own bodies, we can be the primary source in deciding on therapies. Tom effectively describes alternative therapies as well as discussing conventional medical treatment. Living With Aids also provides us with the basics concerning viral and fungal infections.

Tom O'Connor has been living with ARC for over seven years. The book examines how people with ARC and Aids can improve the quality of their lives - even prevent further immune deterioration. Randy Shilts, author of And The Band Played On, writes that "O'Connor's book is a how-to-survive book that should be handed to everybody who tests positive to the AIDS antibody. The level of research is amazing. The writing is cogent and concise. It offers the array of health alternatives without surrendering to the medieval all-things-Western-are-bad ethos."

To readers of ALERT, Living With Aids is available for $16.50. ($15 plus $1.50 shipping) In major bookstores, the price is $18.95 plus tax. Send check or money order in the amount of $16.50 to Thomas O'Connor, 3851 - 21st Street, San Francisco, CA 94114; (415) 821-0853.

KS TREATMENT PROMISING

AIDS patients with Kaposi's sarcoma may benefit from treatment with alpha interferon, according to a study published in the journal Lancet by scientists at the National Institute of Allergy and Infectious Diseases. Dr. H. Clifford Lane, NIAID, and his colleagues have shown that alpha interferon has both anti-retroviral and anti-tumor effects in patients with early AIDS and Kaposi's sarcoma, a systemic cancer that primarily affects AIDS patients.

Approval of alpha interferon for the treatment of AIDS-associated Kaposi's sarcoma was announced the end of November by the Food and Drug Administration. The approval was based in part on data from Dr. Lane's study, which determined that the drug is most effective in those patients whose immune systems are less damaged by infection with the human immunodeficiency virus (HIV), the cause of AIDS.

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(KS Treatment Promising; Cont'd)

Patients who experience the most beneficial effects of high doses of alpha interferon are those who have CD4 (T4 helper) cell counts of more than 200 and who have not had AIDS-related opportunistic infections, Dr. Lane found. HIV seeks out and destroys CD4 cells, which are essential to the body's immune defenses.

Alpha interferon, a naturally occurring protein produced in quantity through recombinant technology, has anti-tumor, immunomodulatory, and anti-viral activities. It has been studied for at least 6 years in AIDS patients as a treatment for Kaposi's sarcoma. While tumor regressions have been seen in between 20 and 67 percent of the patients, scientists have not known whether the results reflect an anti-tumor effect alone, whether alpha interferon acts by boosting the immune system, or whether the drug acts against HIV itself.

To assess the anti-retroviral effects of alpha interferon, Dr. Lane conducted an open trial using the highest tolerable doses of the drug. Twenty-one patients with AIDS and Kaposi's sarcoma received daily subcutaneous injections of the drug, beginning at 35 million units per day and reduced as necessary to manage toxicity. Adverse reactions to the drug include flu-like symptoms and, less commonly, more severe side effects. After 12 weeks of treatment, Dr. Lane assessed each patient's dose regimen and made additional changes.

"The patients' responses closely correlated with their immune function, as measured by their CD4 lymphocyte counts," Dr. Lane said. Eight patients had complete or partial tumor remissions; all of the five who had complete remissions of tumors had CD4 counts of more than 400 cells per cubic millimeter in peripheral blood at the beginning of treatment.

Viral cultures and tests of p24 antigen, which measure HIV activity, changed from positive to negative in several patients. The anti-HIV effect was seen only in those patients with the best immune function who received long-term, high-dose therapy. When the treatment had to be withdrawn because of side effects, as happened in 9 of the 21 patients, or the dosage had to be reduced, virus production returned rapidly.

"Our results show that alpha interferon has a promising anti-HIV effect and can improve the quality of life for certain patients with AIDS," Dr. Lane said. The study, he added, has provided the scientific rationale for additional studies of alpha interferon in patients with early stages of HIV infection. Volunteers at early stages of HIV infection are now being sought for an NIAID study comparing treatment with alpha interferon plus zidovudine (commonly known as AZT) to treatment with zidovudine or alpha interferon alone. Interested individuals should call Victoria Davey, R.N., at (301) 496-7196.

A CHRISTMAS REFLECTION

(By Rev. Steve Pieters)

This is my fifth Christmas living with AIDS. Each Christmas has been different: I have experienced each holiday season with a variety of feelings, ranging from downright depression, anger and fear, to hopeful joy and a poignant sense of celebration. Each year I become more aware of a special appreciation for the birth of Jesus Christ: for now, having faced death in the way that I have, I feel more fully alive than ever before, and each year with AIDS the Christmas gift of God's presence with us--Immanuel--becomes more and more important to my survival, and to my ability to cope with the epidemic surrounding us all.

Christmas, 1983, -- before I was diagnosed with Kaposi's Sarcoma and Lymphoma -- was one of the most fear-filled and joyless holiday seasons in my life. I was terribly sick with an infection on my right foot that no doctor had been able to successfully treat for nine months. My doctor had warned me that my immune system was "severely deficient," and although they had not yet discovered the virus, and so could not test me for an antibody, it was pretty clear that I was coming down with AIDS. I went to my parents home in Arizona for the holiday that year. All of their attempts at creating a joyful atmosphere were filtered through my fear and depression. They gave me crutches, among other gifts, and this confirmed my growing self-image as a chronically ill person, who might never enjoy good health again. I was quite literally scared to death, paralyzed by my fear of being diagnosed with AIDS. As my faith shook from the overwhelming fear of AIDS, I didn't see much to celebrate in this Christmas.

After the shock of my diagnosis in April, 1984, I decided to celebrate Christmas in July that year, since at least one health professional had told me I wouldn't live to see 1985. I had a profound sense of regret that I had lost Christmas 1983 to my fear and anxiety. So I sent out Christmas cards to everyone I could think of, in time for July 25. I was being ruled by the fear that I would not be healthy enough to enjoy another Christmas, and so I manically tried to create the holiday spirit all around me. Christmas in July, 1984, was a Christmas of desperation.

When Christmas really did role around that year, I was elated that I was enjoying good health, and was not going to die before 1985, as predicted. This Christmas was filled with wonder and joy. I was learning to relax and to heal my fear with love, and Christmas became a time of celebration and giving, out of gratitude for the sense of life in the face of AIDS. This was the Christmas I really began to understand the way that God is with us, as I learned to stop worrying about the future (when will I die?) and began to concentrate on each present moment of life.

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(A Christmas Reflection; Cont'd)

At Christmas, 1985, I was taking my 38th dose of suramin, a very toxic experimental antiviral drug. My cancers had gone into complete remission, but I had very nearly died from the toxic side effects of the drug. The joy of the miracle of remission was tempered by the obvious wasting that was happening to my body. I didn't know quite what to feel, but I threw myself into Christmas, once again fighting off the fear that this would be my last holiday season, by concentrating on the sense of love and peace that infects so many people each December. A very loving man came to visit me from the East (Chicago!), and I discovered this Christmas that love really can cast out fear.

After I got off suramin in January, 1986, I got better, and I have not had any opportunistic infections since that time. This miracle has filled each new Christmas with joy and gratitude. Somehow when life is threatened, life becomes all the more precious, and celebrations like the December holidays can be the perfect opportunity to celebrate all that is good about life, even in the face of something as life-threatening as AIDS.

But even long term survivors live with the reality of the massive numbers of deaths happening around us. UFMCC has been hit hard in recent months, practically each week bringing the news of another death in the Fellowship. It is easy to slip into depression and fear as we face the expectations of a joyous holiday season. Don't people know that too many of our friends and family members have been ripped away from us this year? How can we celebrate when our own lives are threatened, not only by this disease, but by the doom and gloom pronounced all around us?

It is precisely at such times that we need to remember the spirit of the message delivered by the one whose birth we celebrate: the miracle of hope, healing, and new life, even in the face of the tragedies and brokenness of this world. We who have AIDS are entitled to hope and joy. We can hope for healing, and for long-term survival (and there are more and more of us long-term survivors!). And even if we are dying, we can enjoy the peace and beauty of the season. As a matter of fact, I have seen people who are dying teach others how to really celebrate the holidays!

Doctors may have told us "the worst news possible," but we can still fully enjoy the holiday season. Indeed, if we are open to it, the real celebration of Christmas, new birth, new life, arises out of the painful awareness of death and dying happening all around us. We can love and cherish our friends and families, we can celebrate with the best of them, and we can be fully alive, trusting that God is with us in every day of our lives, in every aspect of living with AIDS, even in the dying.

One of my favorite names for Jesus is "Immanuel," which means "God with us." I am absolutely convinced, on my fifth Christmas living with AIDS, that nothing, not even AIDS, not even dying, can separate us from the reality of "Immanuel," the reality of God's love and peace with us. It is God's radical "with-ness," in Jesus Christ, which is our greatest Christmas present, a resource that enables us to be fully alive, even in the face of AIDS, even in the face of death and grief.

NIAID ESTABLISHES NEW COMMUNITY PROGRAMS FOR CLINICAL RESEARCH ON AIDS

The National Institute of Allergy and Infectious Diseases is establishing new Community Programs for Clinical Research on AIDS, to involve community physicians in AIDS research. The effort will be coordinated by Lawrence Deyton, M.S.P.H., M.D., who has been appointed to head the recently created Community Clinical Research Section in NIAID's extramural Acquired Immunodeficiency Syndrome Program (AIDSP). Dr. Deyton will also serve as NIAID Assistant Director for Community Research; in that capacity he will advise NIAID Director Anthony S. Fauci, M.D., on issues related to community-based research.

In announcing the initiative, Dr. Fauci said, "These new programs will broaden the base of our clinical investigations by including primary care physicians who are not affiliated with AIDS research efforts that are currently supported by NIAID. We are pleased to create a way to draw on the enthusiasm and experience of community physicians and their patients who wish to have greater involvement in the national research effort on AIDS.

"Through these programs," Dr. Fauci said, "we also hope to include in clinical trials more HIV-infected black and Hispanic persons and intravenous drug users, and more women at risk of HIV infection. HIV infection is increasing rapidly in all of these groups."

The community programs will operate separately but be coordinated with NIAID's nationwide treatment evaluation network which was established in mid-1986 to conduct collaborative clinical trials of experimental therapies in persons infected with HIV. To date, more than 5,000 persons have participated in NIAID-sponsored protocols at member institutions of the AIDS Clinical Trials Group (ACTG). The ACTG now includes 45 AIDS Clincil Trials Units, 13 of which are for pediatric AIDS, in 16 states. Drugs under study include antiretroviral agents, biological response modifiers, and drugs for opportunistic infections and cancers. Studies cover the full range of HIV infection and include asymptomatic HIV-positive persons and children.

NIAID STARTS CLINICAL TRIALS USING SOLUBLE rCD4

(from NIAID AIDS AGENDA, National Institute of Allergy and Infectious Diseases, November, 1988 issue)

NIAID and Biogen, Inc., a biotechnology company located in Cambridge, Mass., are sponsoring a clinical trial of Biogen's version of recombinant soluble CD4 in patients infected with HIV.

The study is being conducted by Robert Schooley, M.D., Mass. General Hospital, Boston, a Harvard Medical School affiliate, and David Ho, M.D., Cedars-Sinai Medical Center, University of California, Los Angeles. The two medical centers are part of NIAID's AIDS Clinical Trials Group (ACTG), a nationwide, multicenter network of experi- enced clinical investigators who collaborate in the evalua- tion of experimental drugs for AIDS and AIDS-related conditions.

The Phase I dose escalation study, which is designed to determine the safety of the drug in humans, is being conducted initially in approximately 25 patients with AIDS and AIDS-related complex.

In announcing the study, Dr. Anthony S. Fauci, NIAID Director, said, "This collaboration with Biogen is an excellent example of how NIAID is cooperating with biotechnology companies to hasten the development and testing of new drugs for AIDS."

Scientists at Biogen, in collaboration with researchers at Mass. General Hospital, showed in labor- atory experiments that their recombinant soluble CD4 product blocked direct infection of T4 cells by HIV as well as cell- to-cell transmission of the virus.

Biogen scientists head one of NIAID's National Cooperative Drug Discovery Groups (NCDDGs), which are teams of experts from biotechnology companies, pharmaceutical houses, universities, medical centers, and Federal agencies. The overall goal of the NCDDGs is to develop new AIDS drugs targeted to specific cellular or viral proteins. Smith, Kline and French and GeneLabs, both participants in the NCDDG program, also have CD4 products in preclinical research.

During the past year, the staff of the NIAID AIDS Program has been working with these groups and others to bring CD4 products to clinical trials. The Institute is collaborating with Genentech, which recently launched the first human trials of rCD4 at three medical centers. If data from these studies are promising, NIAID will encourage the various companies to conduct further studies through the ACTG.

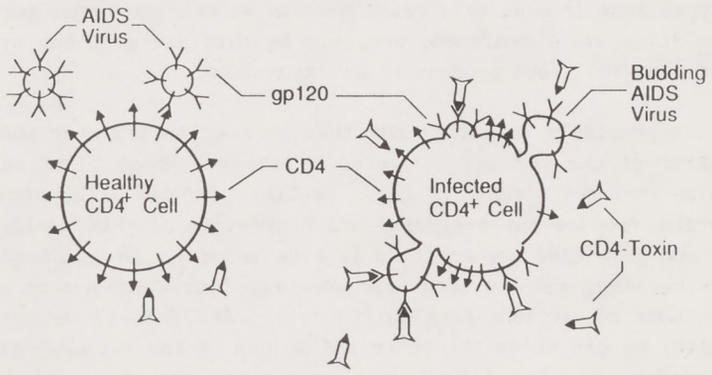
THE IMPORTANCE OF CD4 IN TREATMENT RESEARCH

(from NIAID AIDS AGENDA, November, 1988 issue)

The human immunodeficiency virus (HIV), which causes AIDS, cripples the immune system by attacking and destroying specific immune cells, especially T4 cells and monocyte/ macrophages. These and a few other cell types have on their surfaces a receptor, a protein known as CD4.

Scientists have shown that to gain entry into human cells, the envelope (outer coat) protein of HIV attaches to the CD4 receptor. This discovery spawned the idea of cloning copies of the CD4 molecule or parts of it and then trying to fool the AIDS virus into attaching itself to this free-floating or soluble CD4 rather than to healthy cells.

Through genetic engineering, scientists in a number of laboratories have made synthetic versions of CD4. Their products are called recombinant soluble CD4, rCD4, or recombinant soluble T4 receptor analog. In the test tube, these products have been shown to bind to HIV and neutralize the activity of the virus. In addition, rCD4 has been shown to be safe when tested in laboratory animals. These findings have generated great interest among researchers attempting to find new drugs to treat persons infected with HIV.



The gp120 on the AIDS virus recognizes CD4 on the healthy cell (left). This allows the virus to attach to and enter the cell. The infected cell (right) becomes an AIDS virus factory, manufacturing all virus components including gp120, which accumulates on the cell's surface. New viruses bud off (leave) the infected cell. CD4-Toxin seeks out and kills HIV-infected cells.